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Caregiving in Social Context

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ABSTRACT

The heterogeneity of family caregiving is explored with specific emphasis on differences by gender, age, race, and area of residence. The aging of the population and other social structural changes during the next several decades will simultaneously increase the size of the population in need of long-term care and constrain the options available to frail elders and their care providers. Research suggests that there will be particularly deleterious consequences for women, older elders, nonwhites, and those who live in rural areas. In addition to these social characteristics, elder abuse and neglect, negative outcomes sometimes associated with caregiving, and the importance of linkages between formal and informal providers are discussed. Finally, the many contributions of older people to society and the fact that most elders are aging well are addressed. The modification of curricula to reflect caregiving in social context will enhance training programs designed for formal and informal providers who work with impaired elders and formal courses available to students in academic institutions. The latter represent future decision makers who will have the opportunity to influence public policies and intervention strategies whose benefits will redound to frail elders and their care providers.

ARTICLE

There are now more than 30 million people age 65 or older in the United States. That fact, combined with projections indicating that this number will more than double by 2060 (U.S. Bureau of the Census, 1989), has spurred debate about how private and public resources should be allocated to meet the needs of frail members of this population. Annual expenditures on institutional and in-home care for chronically impaired older adults total more than $100 billion (Levit, Lazenby, Cowan, & Letsch, 1991); however, 80% of those who require long-term care are cared for in the community and receive most or all of their assistance from family members (Dwyer & Coward, 1992; Scanlon, 1988). Hence, long-term care policy has relied on "free" care provided by family members.

This trend, along with long-term changes in social structure affecting both the availability of informal care providers and the normative obligation to provide caregiver support, means that current long-term care policy must either adapt or fail to meet the needs of a rapidly increasing number of older adults (Dwyer, in press; Goldscheider, 1990). Unfortunately, there are few signs that the current policy is adaptable or that policymakers are willing to address these issues comprehensively. The current draft of the Clinton health care reform plan, for example, provides for enhanced in-home care resources only after impairments in three activities of daily living (ADLs) are present. As most providers and caregivers know, substantial care is usually required well before this advanced level of frailty is documented.

The demography of caregiving indicates that providing care for older people has been a significant social issue for only the last quarter century. In 1900, there were only 3 million people over the age of 65, the leading causes of death for elderly people were acute conditions such as influenza and pneumonia (Crandall, 1991), and the majority of middle-aged couples had no living parents (Uhlenberg, 1980). In contrast, there are 6--10 million functionally impaired older adults living in the community today (Coward, Cutler, & Mullins, 1990; Macken, 1986); the leading causes of death are conditions such as heart disease and malignancies, typically preceded by long periods of chronic impairment (Crandall, 1991); and many people, even among those over the age of65, have living elderly parents (Coward, Horne, & Dwyer, 1992).

Aging policy during the 20th century also suggests that the reliance on informal care providers as the primary source oflong-term care is a relatively recent phenomenon. At the beginning of the 20th century, in addition to being few in number and remaining relatively healthy until they died, older family members usually retained economic control of their holdings. Thus, physical or economic dependency was not normative (Haber, 1983). However, as industrialization increased during the early part of the 20th century, aging, and in some ways the elderly themselves, came to be perceived as a social problem. By the 1930s, old-age pensions were common, and support for the dependent aged was increasingly shifted to the public sector (Axinn & Stern, 1985). Between 1930 and 1960, these changes had the effect of simultaneously relieving families of some caregiving responsibilities and driving the growth of a human services bureaucracy to meet the needs of the elderly population (Dwyer & Coward, 1992; Fischer, 1978).

The inability of the array of public programs initiated in the 1960s to provide adequately for older citizens, coupled with the economic decline of the 1970s and 1980s, converged to increase the use offamily care giving systems, on the basis of "the erroneous assumption that informal structures for providing care were underutilized and simply needed to be activated" (Hooyman, 1990, p. 223). At the same time, longer life expectancy and generally declining fertility rates have increased the likelihood of multigenerational family structures and reduced the number of family members in anyone generation. As Conner (1992) noted, "while the average number of horizontal relationships in the typical family has declined, the average number of vertical relationships has increased" (p. 105).

Changing social structure and the limitations of current public policy have particularly deleterious consequences for certain subsets of the older population. Moreover, the traditional educational approach, which views the older population as a homogeneous group lumped together under the convenient but overused label "the elderly," is no longer sufficient. Gerontologists' ability to design and implement policies and intervention strategies that will meet the needs of elders and their care providers into the 21st century is largely dependent on understanding the heterogeneity of the population and the unique needs of significant subgroups. The diversity of this population also requires that educators in gerontology make their students aware of the social characteristics that dramatically affect an individual's long-term care options.

Our purpose in this article is to explore the social context of family caregiving by focusing on four significant social characteristics: gender, age, race, and area of residence. Although the now voluminous caregiving literature provides important insights into these distinctions, our reviews are necessarily brief and intended simply to raise awareness of significant issues. We also discuss elder abuse and neglect as negative outcomes that sometimes result from caregiving situations and the importance of linkages between formal and informal care providers. Understanding these caregiving dimensions and issues may enhance gerontologists' ability to educate caregivers, providers, and students who may be involved as direct care providers; may influence public policies; and may contribute interventions targeted to specific types of frail elders and the individuals who care for them.

GENDER

It is now generally accepted that gender is one of the principal differentiating characteristics of the caregiving milieu. Most elderly people in need oflong-term care are women, and the majority of the caregiving assistance provided by families is provided by women. Because the caregiving burden is borne almost exclusively by women, intervention strategies and public policies should be targeted to their needs.

Older Adults

Because women live longer and are less likely to suffer from fatal chronic conditions, most older adults who need long-term care are women (Lee, 1992; Verbrugge, 1989). In the general population over age 65, the ratio of women to men is 1.5 to 1. However, among those age 65 or older who are impaired, the ratio of women to men is approximately 2 to 1 (Manton & Soldo, 1985; Verbrugge, 1989). Women are more likely than men to be institutionalized CHing, 1987); to be cared for by an adult child rather than a spouse; and, when living in the community, to be unmarried and childless (Himes, 1992). Hence, women typically have fewer options for caregiving assistance. Goldscheider (1990) highlighted the gendered orientation of caregiving by arguing that among those who need caregiving assistance, "the poor and solitary are very likely to be women" (p. 535).

Caregivers

The likelihood of becoming a caregiver follows a hierarchical pattern with respect to the relationship ofthe caregiver to the care recipient: A spouse is most likely to be the primary caregiver. In the absence of a spouse, adult children usually provide care, followed by other family members (e.g., siblings or grandchildren), and then neighbors and friends (Horowitz, 1985; Stoller, 1992). Yet within type of relationship, wives more often care for husbands than vice versa (Tennstedt, McKinlay, & Sullivan, 1989), because women live longer and tend to marry men older than themselves; daughters are three times more likely than sons to provide care when other characteristics likely to affect caregiving behavior are controlled (Dwyer & Coward, 1991); and sisters are more likely than brothers to provide care (Matthews & Rosner, 1988). Indeed, in one study, 80% ofthe unmarried frail elderly living in the community were cared for by women (Soldo & Myllyluoma, 1983).

The overwhelming reliance on women as the principal long-term care resource in the United States is problematic. From a structural perspective, the competing social demands that confront women (e.g" participation in the labor force and the economic consequences of divorce) will increasingly reduce their ability to provide the personal, intensive, and ongoing care often required by impaired older adults (Dwyer, in press). Future cohorts of women may also be less likely to adhere to the same filial norms and obligations as their predecessors. Finally, when men do participate in caregiving, they are more likely than women to be secondary, rather than primary, caregivers (Coward & Dwyer, 1990); are less likely than women to be care providers and more likely to be care managers (Archbold, 1983); and are more likely than women to be backup or sporadic caregivers, to provide circumscribed care, or to provide no assistance at all (Matthews & Rosner, 1988).

There is also an attitudinal/psychosocial dimension to caregiving that is gender specific. In analyzing results from the 1982 National Informal Caregivers Survey, Dwyer and Seccombe (1991) found that husbands reported more time spent caregiving and accomplishing more care giving tasks than did wives. Similar reports by son and daughter caregivers were not statistically different. The authors explained these counterintuitive findings as probably due to the fact that

men and women define the context of caregiving differently. The tasks usually associated with caregiving are those that have also traditionally been referred to as "women's work." Hence, when asked ifhe does the laundry or cooks *as a result of his wife's disability,* a husband is likely to respond in the affirmative. A wife, when asked the same question, typically responds in the negative, because these are tasks that she has always performed and have little to do with her spouse's disability.

AGE

Increased life expectancy and the dramatic growth in the older adult population that will occur during the next several decades underscore the need to focus on age differences as they relate to both the needs of care recipients and the responsibilities of care providers. The changes in the American age structure that will begin around 2005 as the baby boomers reach older ages are likely to have a profound impact on the types and amount of care that can be provided by the informal care system.

Older Adults

Whereas the population age 65 or older is projected to more than double by 2060, the population age 85 or older will increase more than sixfold (to 18 million) during the same period (U.S. Bureau of the Census, 1989). This demographic "imperative," as it is sometimes called, is important because the oldest old (85+) are at much greater risk of being institutionalized than are younger cohorts of older adults (Rivlin, Wiener, Hanley, & Spence, 1988). Furthermore, not only does the incidence of disabling chronic conditions increase with age (Verbrugge, 1989), but also the proportions of the population who are women and who are unmarried increase (National Research Council, 1988). Indeed, Himes (1992) has projected that by 2000, approximately 20% of women over the age of 85 will be unmarried and childless. These women are at exceptionally high risk of needing some form of supportive care services. The fact that they lack the most common sources of caregiver support-spouses and adult children-implies that their only option may be some form of in-home or institutional care.

Caregivers

Because the caregiver's age reflects both the intensity of the care she or he provides and the difficulty of providing care, it is a critical variable in the study of elder care. As the age of an impaired older adult increases, the likelihood that the caregiver will be a nonspouse relative also increases (Dwyer & Coward, 1992). There is also a greater likelihood that the caregiver will be an older adult caring for a parent or parent-in-law (Coward, Cutler, & Schmidt, 1989). Furthermore, unique to the coming decades is the chilling prospect that more older caregivers will be called on to provide care simultaneously to both a frail spouse and an increasingly dependent parent. Moreover, many will spend more years providing care to elderly relatives

than to children (Older Women's League, 1989; Stone, Cafferata, & Sangl, 1987). As greater numbers of adult children, primarily daughters, become caregivers as a result of the aging of the population, the impact of competing demands will become even more important. By 2000, for example, it is projected that 76.5% of women ages 45-54 and 49% of women ages 55-64 will be in the full-time labor force (Shank, 1988).

RACE

The number of older Mrican Americans doubled between 1960 and 1990 from 1.2 million to 2.6 million. In part as a result of better health care and attendant increases in life expectancy, the number of elderly people of color is projected to triple to 7.8 million by 2030 (Angel & Hogan, 1991). Long-term care policies have never adequately addressed minority issues. The magnitude of the projected increase in the size of this population is likely to exacerbate an already difficult problem.

Older Adults

Older adults of color are more likely than older white adults to experience chronic disabilities (Markides & Mindel, 1987), yet they are less likely than older whites to be institutionalized (Dwyer, Barton, & Vogel, 1994; Greene & andrich, 1990). Specifically, older African Americans are about half as likely as whites to use long-term care institutions (Crystal, 1982). The expected growth of the minority elderly population, coupled with characteristically poorer health and higher rates of poverty (Chen, 1991), places them at increased risk of not receiving the long-term care services they require. In addition, projections indicate that older African American women are more likely than older white women to be without a spouse and children as their age and need for long-term care assistance increase (Himes, 1992).

Caregivers

The limited use of long-term care institutions by minorities, particularly by African American elders, has frequently been tied to stronger familial support networks (Crystal, 1982). Yet evidence suggests that older adults of color are no more likely to receive assistance from their children (Mindel, Wright, & Starrett, 1986) or to live in a shared household with kin (Soldo, Wolf, & Agree, 1990) than are other segments of the older population. What this means, of course, is that the incorrect but general perception that minority families are more likely to "take care of their own" is especially harmful. Because older adults of color are underrepresented in long-term care institutions and are no more likely to receive certain forms of informal family care than other segments of the older population, many of them must fend for themselves. Present long-term care policies that depend on informal caregivers to meet the needs of minority elders are based on incorrect assumptions and must be reassessed in the near future.

AREA OF RESIDENCE

Older Adults

Approximately one fourth of all older adults in the United States live in nonmetropolitan areas (U.S. Senate, Special Committee on Aging, 1992). Although most differences in health status between rural and urban elders disappear when other population characteristics are controlled (Cutler & Coward, 1988), disparities in the availability, awareness, and use of formal services persist (Dwyer, Lee, & Coward, 1991). For example, older adults living in rural areas are less likely than those living in urban areas to participate in health promotion activities (Lubben, Weiler, Chi, & DeJong, 1988), to benefit from Title XX social service dollars (Nelson, 1983), and to have access to programs and services designed to meet the needs ofthe most severely impaired older adults (Sharp, Halpert, & Breytspraak, 1988). As a result, rural elders are at risk of entering nursing homes at younger ages and in better health than their urban counterparts (Dwyer et aI., 1994; Greene, 1984).

Caregivers

Rural elders are also more likely than urban elders to live with a spouse (Coward et aI., 1989), to have living children (Lee, Dwyer, & Coward, 1990), and to have family members available to provide assistance. Although research from the last decade reveals that rural elders are no more likely than urban elders to be embedded in supportive social networks (Dwyer et aI., 1991), the helping networks of the rural elderly are more likely to consist exclusively of informal sources of support (Blieszner, McCauley, Newhouse, & Mancini, 1987). Related research also indicates that characteristics of care giving situations have differential effects across residential categories (i.e., rural, small city, and urban area) in terms of the stress and burdens placed on primary caregivers (Dwyer & Miller, 1990). Caregivers in rural categories consistently report more stress, more burden, and less external assistance than do caregivers in urban areas.

ELDER ABUSE AND NEGLECT

Because we choose our friends but not our family, because perceived obligations to family members are at least as strong as those to our friends, and because the family is such an emotionally bonded primary group, it is inevitable that taking on a caregiving role for a dependent elder can create or add to strain in numerous ways. Elder abuse and neglect can be unfortunate outcomes of such intrafamilial strain. Research has identified abuse and neglect risk factors for caregivers, care recipients, and the family system. In general, the lack of anticipation or preparation by any or all parties increases the odds of strain and, thus, abuse (Steinmetz, 1988), as do emotional problems that negatively affect interpersonal relationships (Godkin, Wolf, & Pillemer, 1989). Family system risk indicators include financial strain, marital problems, and lack of family support for caregiving (Kosberg, 1988). Finally, recipient traits are less powerful predictors of abuse and neglect than are caregiver traits (Pillemer & Finkelhor, 1989).

Older Adults

For the elderly care recipient, risk factors typically mentioned include being female, being of advanced age, and having alcohol problems (Kosberg, 1988; Steinmetz, 1988). But identification of risk factors remains inconclusive. For example, whereas some researchers have linked abuse and neglect risk to higher levels of dependency or multiple demands (Kosberg, 1988; Steinmetz, 1988), others have found that increased needs are not significantly related to the likelihood of abuse (Godkin et al., 1989; Pillemer & Finkelhor, 1989). In addition, Finkelhor and Pillemer (1988) have reported that whereas abuse of older women was more severe, older men were more likely to be abuse victims. Finally, Pillemer (1985), using samples of abused and nonabused elderly matched for gender and living arrangement, found that abused older persons were younger, less impaired physically, and less dependent physically and economically than nonabused older persons.

Caregivers

Caregivers who abuse or neglect their charges are more likely to have a substance abuse problem or other "deviant" traits, be inexperienced in the caregiving role, have financial problems, be highly dependent (e.g., financially) on the care recipient, and be subjected to constant criticisms (Godkin et al., 1989; Kosberg, 1988; Pillemer & Finkelhor, 1989; Steinmetz, 1988). Spouses and sons are more likely than daughters to abuse (Finkelhor & Pillemer, 1988). The application of this knowledge has lagged far behind other efforts to address the needs of caregivers and their frail older relatives. Beyond a recognition that caregiver stress may be an important contributing factor in cases of elder abuse, few interventions based on this knowledge have been attempted.

LINKING FORMAL AND INFORMAL CAREGIVING

A review of caregiving in social context cannot ignore the actual and potential linkages between the family (or other caregiving) unit and the formal caregiving system. The investigation of such linkages must examine both structure and process, because each has an impact on outcomes. Noelker and Bass (1989), studying personal care and home health services for persons age 60 or older, identified four categories of the intermingling (or lack thereof) of family caregivers and service agencies: kin independence, formal service specialization, dual specialization, and supplementation. The family-agency relationship is shaped by the caregiver's and care recipient's needs, family history, family resources, and service provider availability. Further evidence of the real and perceived benefits of informal-formal caregiving linkages was provided by a survey of 76 local agency administrators (Linsk, Osterbusch, Simon-Rusinowitz, & Keigher, 1988). Fifty-six percent of the respondents either found it cost-effective to hire family members as caregivers or said they would hire family members if sufficient resources were available.

Another argument for formal-informal linkages and for flexibility of care arrangements stems from findings that the quality of the relationship between the caregiver and care recipient is

highly predictive of the care recipient's level of satisfaction. This finding holds regardless of the recipient's level of functioning (Parsons, Cox, & Kimboko, 1989). While family members are usually the recipient's first choice to be caregivers, good relations-and thus high satisfaction-are not restricted to family. Comparing hospital patients discharged to nursing homes with those discharged to foster homes, Oktay, Horwitz, and Volland (1988) found that the latter scored higher on functional measures and nursing goals. They also found foster home caregivers to be actively interested in the aged, happy to be able to work at home, and desirous of delaying or preventing institutionalization of the care recipient.

MEASURING AND PREDICTING QUALITY OF CAREGIVING

The increase in research on factors linked to successful and problematic caregiving suggests the development of instruments that can predict caregiving obstacles for caregivers, care recipients, and families. If such instruments can be validated through careful testing, the information they yield should allow a more effective use of resources to assist potentially dysfunctional caregiving arrangements. In the caregiving environment, prevention is preferable to intervention. Two examples of this are the Beliefs About Caregiving Scale (Phillips, Rempusheski, & Morrison, 1989) and the QUAL CARE Scale (Phillips, Morrison, & Chae, 1990a, 1990b). The former, tested in four studies, focuses on identifying caregivers likely to provide low-quality care to a dependent older person. The QUAL CARE Scale, tested on nearly 250 caregiver-recipient pairs, evaluates the quality of care provided by family members to older persons. Physical, medical, financial, psychosocial, human rights, and environmental dimensions are included.

As caregiving patterns and issues continue to be described in increasing breadth and depth, there is no reason why research cannot simultaneously move toward testing and validation of measures of caregiving quality. The transformation of findings into applied tools will be of great use to the growing numbers of caregivers, care recipients, and related helping professionals.

FUTURE RESEARCH NEEDS

Despite the large and growing literature on caregiving, there are several areas in which our present understanding remains limited. This section identifies four areas of research that could yield better information than is currently available to formal care providers, policymakers, informal caregivers, and older adults.

First, more research is needed that highlights the heterogeneity of caregiving situations and relationships. For example, although research typically focuses on the impaired and frail elderly, more emphasis should be placed on understanding those tasks that even disabled elders can perform. Some recent research has indicated that the well-being of older adults as well as the stress and burden associated with caregiving may be influenced directly or indirectly by the degree of the older person's reciprocity in the care giving context (Dwyer, Lee, & Jankowski, 1994). To put it simply, those older adults who are perceived as helpful produce a care giving

experience that is less stressful for the caregiver, resulting in better care. More attention should also be given to the heterogeneity of the older population, including interactions between two or more social characteristics. For example, rural African Americans appear to be especially at risk of not having access to institutional care (Dwyer et al., 1994), and older African American women are at greatest risk of having neither a spouse nor a child as a care giving resource in old age (Himes, 1992). The size of certain subgroups within the older population, even when cross-classified by indicators such as gender and residence or gender and race, is sufficient to warrant the use of appropriate research techniques as well as policies targeted for their benefit.

A related concept that deserves further exploration, especially in view of the traits and situations of older persons, is fictive kin. Scott and Black (1989) suggested that the study of the African American family has been hampered by the historical use of the Anglo family structure as a frame of reference. They then argued for the recognition of fictive kin as an element of the kinship structure of the Mrican American family; the tendency is to develop fictive family relationships in new situations and to create fictive kin when there are no relatives. In a study of older African Americans and whites, Johnson and Barer (1990) found a propensity among African Americans to use fictive kin to expand their family networks. African Americans were also more likely than whites to rely on their church to relieve social isolation, and to have contact with their relative and friend networks. Fruitful findings could emerge from further study of the reasons behind and functions of fictive kin.

Third, a glaring deficiency in the caregiving literature is the focus on proximal events to the near exclusion of distal events. Because the effects on caregiving situations oftransitions and events that occurred earlier in both elders' and the caregivers' lives have not been explored, a great deal of understanding regarding the caregiving milieu has been missed. Bedford (1992) found, for example, that memories of being the least favored child affected the quality ofthe parent-child bond in later life. Preliminary results from a more recent study indicate that early life separations from parents affect the later life caregiving behaviors of adult children (Dwyer & Henretta, no date). Goldscheider (1990) has also argued that early life separations due to divorce may reduce the normative obligation to provide care to the separated parent (usually the father) later in life. Greater understanding offamily history factors that may influence the initiation, quality, and quantity of care would be useful.

Finally, caregiving relationships and situations should be viewed as fluid rather than static. Although Stone et al. (1987) reported that a large number of caregivers in the 1982 Informal Caregivers Survey had provided care for more than 6 years, more recent findings suggest that, among adult children, caregiving is much more sporadic. Dwyer, Henretta, Coward, and Barton (1992) reported that 50.7% of sons and 29.9% of daughters who were providing care at baseline were no longer doing so 2 years later. Moreover, even after a number of variables likely to influence the provision of care were controlled, daughters were more likely than sons to sustain caregiving over the 2-year period. Having an understanding of the dynamic nature of the caregiving environment will help gerontologists provide policymakers with more accurate assessments ofthe potential effectiveness of policies designed to support the provision of long-term care by family members.

The social context of caregiving requires that educators understand the interconnectedness of the issues involved. If the veritable explosion of gerontological research on caregiving experienced in the last decade appears somewhat unfocused and confusing, one thing remains clear: Neither caregiving nor its impact on the lives of those who provide it and those who receive it can be considered outside ofthe social context within which it is expressed. Gerontological educators have a long history of concerning themselves with debunking the myths and stereotypes associated with aging. To accomplish this, they have often found it necessary to approach aging as an event that can be isolated from other personalized events. In light of the challenges, problems, and opportunities that will be present in the 21st century, educators would be wise to reinvent an orientation that recognizes the particular social context within which people are born, age, and die.

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